

Testimony in Support of SB 200

An Act Expanding Health Insurance Coverage of Specialized Formula

Insurance and Real Estate Committee

March 6, 2014

My name is Nancy Mahmoud from Westport, CT and I am testifying in support of SB 200 to expand coverage of medical food.

In 2008, my son, Zane, was diagnosed with an EGID, a genetic disorder prohibiting him from eating. When he does eat, white blood cells, called eosinophils, attack his digestive system. Prior to his diagnosis, Zane had three surgeries and multiple hospital stays for malnourishment and dehydration. He went from the 90% at birth to the 30%. He was vomiting twenty or thirty times a day and suffering from starvation.

Presently, medical food is Zane's main source of nutrition. Steroids allow him to consume a small amount of food a day. Prior to Zane's surgery to have a feeding tube in place, he lost approximately 15 pounds at the age of 4. He was lethargic, unable to walk, focus, or perform basic tasks like dressing himself. He also missed three months of school. He suffered from extreme hunger and developed behavioral problems. Medical food is the only FDA approved treatment for kids with EGIDs. According to APFED, only 15% of kids with an EGID rely on it in some part for nutrition. So, approximately 50 families in CT would be impacted by this bill; a very small subset of a rare disease. Our group, Thrive!, represents approximately thirty families in CT. Almost all of us are on self funded insurance plans. Therefore, the likelihood of expanding coverage affecting CT's state budget under the new ACA rules is slim to none.

It costs approximately \$26,000 / year for medical food and supplies to treat Zane. We pay 30% of that cost. \$26,000 is about 40% of the average CT family's median income. At one point, our insurance company agreed with APRIA to supply us medical food at \$120/ can. Zane goes through a can a day. We are now paying around \$53 / can when we could get it directly from the pharmaceutical company for \$40/can. However, the pharmaceutical company is an out of network provider. Insurance companies profit from medical food.

Much like, Diabetes or PANDA, covering medical food for kids with EGIDs is cost effective preventative care. In 2008, Zane was admitted to the ER at Mt. Sinai Hospital for one hour of hydration and nutrition at a cost of \$950. According to APFED, a 24 hour hospital stay for IV fluid treatment cost an average of \$5500. That would pay for 3 ½ months of medical food for Zane. Families unable to afford medical food may be compelled to feed their children regular foods that could cause permanent damage to their gastro-intestinal system. According to APFED, one year of Total Parenteral Nutrition (TPN) would cost \$1.8 million dollars per patient which insurance companies would have to pay for.

Medical food saved my son's life. The current law presents an obstacle in treatment of care to children with EGIDs. I urge you to follow in NJ and NY's foot steps by providing coverage for children with EGIDs.

Thanks you. I can take questions if there are any.

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